

AWARD NUMBER: W81XWH-12-1-0553

TITLE: Systematic Assessment of Caregiving Skill Performance by Individuals with Tetraplegia and Their Caregivers

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CONTRACTING ORGANIZATION: Kessler Foundation, West Orange, NJ

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14. ABSTRACT The objective of the proposed study is to create an assessment tool for use by clinicians during inpatient rehabilitation to systematically evaluate and describe competence in self-direction of care and caregiving skills. Analysis of focus group data has revealed a number of themes about care direction/caregiving in general as well as specific recommendations for the assessment tool. Participants expressed that successful care director/caregiver interactions require self-awareness, self-advocacy, ability to communicate one's needs clearly and respectfully, knowledge of and ability to convey why tasks must be done a certain way and engagement and cooperation of both parties. Suggestions for the assessment tool included (1) allowing caregiver performance and care director performance to be scored separately and as a team; (2) rating skills in broad functional categories to avoid excessive detail; (3) assessing behavior over a period of time rather than at a single point in time; (4) involving multiple disciplines in scoring; (5) including safety of skill performance (a key criterion for determining readiness for discharge) in the scoring system. An assessment tool ("Teaching Effective Assistance Management" or "TEAM" Tool) and accompanying instruction guide have been created and are currently being piloted. This work will contribute to the process of enabling people with tetraplegia to live healthy and successful lives in the community.					
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Annual Report for 30-Sep-2015 to 29-Sep-2016

1. INTRODUCTION

The objective of the proposed study is to create an assessment tool for use by clinicians during inpatient rehabilitation to systematically evaluate and describe competence in self-direction of care and caregiving skills. These sets of skills are unaddressed by functional outcome measures currently used in inpatient care and rehabilitation research. As a result, current measures are inadequate to describe progress made during inpatient rehabilitation by persons with tetraplegia (PWTs), for whom **training** in self-direction of care and family training in caregiving skills are important areas of rehabilitation intervention. (Note that “caregiving” and “self-care” refer broadly to the performance of basic and advanced activities of daily living (ADLs), medical treatments such as suctioning, mobility, maintenance of a healthy living environment, and all other tasks needed to maintain health, well-being, and productivity for PWTs.) This project will address this gap in assessment by creating a tool specifically designed to assess competence in self-direction of care and caregiving skills. The project has four specific aims: (1) Identify rehabilitation goals related to self-direction of care and caregiver performance of care tasks, indicators of progress toward those goals, and criteria for establishing competency that are meaningful to SCI clinicians, PWTs, and their caregivers. (2) Create an assessment tool that reflects these goals, indicators, and criteria. (3) Assess the comprehensiveness and utility of the tool in inpatient rehabilitation qualitatively, by piloting its use in that setting and obtaining feedback from end-users. (4) Based on this feedback, create a refined version of the assessment tool suitable for further development and evaluation in subsequent research.

2. KEYWORDS

Rehabilitation, spinal cord injury, assessment, qualitative research, caregiving

3. RESEARCH ACCOMPLISHMENTS

What were the major goals of the project?

To achieve the specific aims stated above, major goals for the past year’s activities were to:

- (1) Obtain continuing regulatory approvals for the conduct of human subjects research activities
- (2) Complete focus group recruitment
- (3) Analyze chart review and focus group data to identify themes relevant to the development of the assessment tool
- (4) Draft the assessment tool and instruction guide
- (5) Obtain feedback from focus group participants on the initial draft and revise it to create versions suitable for pilot-testing in inpatient rehabilitation
- (6) Initiate pilot-testing

What was accomplished under these goals?

Major Activities. Major activities (and methodology employed) will be described for each of the goals described above.

(1) Obtain continuing regulatory approvals for the conduct of human subjects research activities

Continuation applications were submitted for all sites to local IRBs and to HRPO and no lapses in approval occurred.

(2) Complete focus group recruitment

A focus group was held by conference call to allow three additional caregivers of people with tetraplegia affiliated with the East Orange VA (EOVA) to participate in the study, bringing focus group recruitment to a close. The final total number of participants is below, followed by data tables presenting characteristics of the focus group participants, by site. All focus groups contained individuals with considerable years of experience. Notably, while the median number of hours of paid care was similar for civilians and veterans, the median hours of unpaid care per week was twice that of the civilian groups (Table 2).

Table 1. Number of Participants Enrolled by Site and Constituency

	Kessler	Shepherd Center	EOVA	<i>Total by Constituency</i>
Persons with Chronic Tetraplegia	9	8	9	26
Caregivers of Persons with Chronic Tetraplegia	4	7	5	16
Clinicians/Health Care Providers	9	9	7	25
<i>Total by Site</i>	22	24	21	67

Table 2. Participant Characteristics for Focus Group Participants with Tetraplegia

	Kessler	Shepherd	EOVA
n	9	8	9
Age in Years [Median (Range)]	44 (29–67)	45 (30-61)	59 (43-81)
Sex [% Male]	67	57	100
Ethnicity [%Hispanic]	11	0	11
Race [% Caucasian]	56	57	33
Years Post-Injury [Median (Range)]	16 (2-50)	20 (1-44)	21 (2-38)
Paid Hours of Care Received Per Week [Median (Range)]	37 (6-56)	35 (9-72)	36 (0-140)
Unpaid Hours of Care Received Per Week [Median (Range)]	10 (2-12)	12 (0-24)	24 (2-168)

Table 3. Characteristics of Caregiver Focus Group Participants

	Kessler	Shepherd	EOVA
n	4	7	5
Age in Years [Median (Range)]	61 (24–70)	52 (43-61)	63 (24-74)
Sex [% Male]	25	14	20
Ethnicity [%Hispanic]	25	0	0
Race [% Caucasian]	50	14	60
Years of Experience Providing Care [Median (Range)]	15 (3-25)	15 (1-35)	4 (2-38)
Hours of Care/Week Provided [Median (Range)]	30 (8-100)	48 (4-120)	40 (10-168)
% Hired (vs. Informal)	25	71	0

Table 4. Characteristics of Clinician Focus Group Participants

	Kessler	Shepherd	EOVA
n	9	9	7
Age in Years [Median (Range)]	39 (28-59)	41 (25-46)	41 (35-53)
Sex [% Male]	0	22	17
Ethnicity [%Hispanic]	0	0	0
Race [% Caucasian]	89	89	17
Discipline [%]			
Nursing	22	33	33
Occupational Therapy	33	33	17
Physical Therapy	33	33	17
Other	11	0	33
Years SCI Rehab Experience [Median (Range)]	12 (4-37)	8 (3-13)	10 (7-21)

(3) Analyze chart review and focus group data to identify themes relevant to the development of the assessment tool

Transcripts for the EOVA groups were completed during the current reporting period (transcripts for groups at other centers were completed prior to the current reporting period.) Chart review and focus group data were analyzed by three investigators (Zanca, Morris, Dijkers). A summary of themes and their implications for assessment tool development has been submitted in previous reports. Key themes that were considered in the development of the tool included the following:

- The types of tasks with which assistance is needed are varied and encompass nearly all aspects of life (not just medical care)
- Each person with tetraplegia has specific needs and preferences for how things are done
- Tasks that could cause medical complications if not done properly were generally considered most important
- Successful direction of care requires:
 - Self-awareness and understanding of your body
 - Ability to communicate your needs clearly and specifically
 - Confidence to self-advocate
 - Problem-solving ability
 - Patience and flexibility (to a point)
- Teamwork is critical; interpersonal skills are important for both care directors and caregivers
- Many factors make direction of care/caregiving skill training challenging during inpatient rehabilitation:
 - Denial of injury and functional status

- Shrinking lengths of stay
- Being overwhelmed
- Difficulty scheduling training with caregivers
- Lack of physical or emotional readiness among caregivers
- Differences between rehab and “the real world”
- Most people with tetraplegia/caregivers reported that experience, trial-and-error were greatest teachers
- Understanding why a particular task needs to be done a certain way is critical to:
 - Engage people who are being trained to direct or provide care
 - Facilitate positive interpersonal dynamics (by giving credibility to the person with tetraplegia and respect to the caregiver’s contribution)
 - Problem-solve
- Clinicians reported several possible ways in which an assessment tool for direction of care/caregiving skills could be helpful:
 - Setting goals
 - Building confidence
 - Promoting conversations about difficult subjects (ability to provide care, willingness, interpersonal dynamics)
 - Planning for discharge (assessing readiness, identifying areas to cover to prepare, etc.)

(4) Draft the assessment tool and instruction guide

Using the themes identified in the focus groups, a draft of the assessment tool and instruction guide was created. The tool was named the TEAM Tool (TEAM = “Teaching Effective Assistance Management”) to emphasize the importance of collaboration and interpersonal interaction to the success of direction of care and caregiving. Key features of the draft of the tool included:

- Three parts (A, B, C) that list tasks with which help may be needed from caregivers
 - **Part A:** Health and/or everyday functioning (“meat and potatoes” of inpatient rehab)
 - **Part B:** Communication-related behaviors
 - **Part C:** Home and community skills, as well as managing hired staff, if applicable (some tasks here may not be addressed until later in rehabilitation process)
- Separate scoring for Care Director, Caregiver, and Team
 - Reflects that each member contributes in his/her own way and that the team has a synergy
 - Provides flexibility in cases where a caregiver is not available for assessment
- Three scales for scoring, each describing different aspects of task performance:
 - Safety (Parts A and C)
 - Problem-Solving (Parts A and C)
 - Communication (Part B only)
- Scores reflect ability to appropriately execute that aspect of task performance *without assistance from the trainer*

- Scores based on performance observed during week preceding tool completion date (allows greater opportunity to observe behavior than would be the case if assessment focused on observations made in a single day or session)

(5) Obtain feedback from focus group participants on the initial draft and revise it to create versions suitable for pilot testing in inpatient rehabilitation

A series of 6 conference calls involving 14 participants (4 people with tetraplegia, 2 caregivers, 8 clinicians) were conducted to share the initial draft of the TEAM Tool and obtain feedback. After each call, adjustments were made to the tool so that feedback on the revised version could be given in subsequent calls. Adjustments were made to the list of tasks to address tasks that were perceived to be missing or needed greater emphasis. Revisions were also made to the scoring system, bringing it from a 6-point system to a 4-point system. This change was recommended by call participants to simplify the process of scoring and align with how clinicians typically think of skill level. The final versions of the TEAM Tool and instruction guide that are being used for piloting are presented in the Appendix to this report.

(6) Initiation of piloting

Piloting was started first at Shepherd Center due to a need to fill an open Research Assistant position at Kessler Foundation that is required to implement pilot testing at that site. Piloting will begin at Kessler at the beginning of the next reporting period. Originally, the plan was that training for Shepherd Center clinicians would happen in a large session conducted by Dr. Zanca in-person at Shepherd Center. Because of the length of the training session (90 minutes) it was necessary to conduct the sessions outside of clinicians' working hours, and we found that offering many options on different days and times was necessary to enable all those who were interested to attend training. As of the date of this report, five training sessions have taken place with Shepherd Center clinicians, utilizing Go-To-Meeting (for which a subscription is already funded by Kessler Foundation) to allow visual interaction of participants with Dr. Zanca and facilitate review of training materials. To date, 16 clinicians have been enrolled and trained (5 Physical Therapists, 7 Occupational Therapists, 3 Nurses, and 1 Speech Therapist). An additional 18 clinicians have been approached about the study. More trainings will be scheduled as additional clinicians express interest in participating (5 have expressed interest in training thus far, and 18 more are considering participation).

Three types of participants are enrolled in the piloting phase: people with acute tetraplegia undergoing inpatient rehabilitation, caregivers associated with those people with tetraplegia, and SCI clinicians. The screening and enrollment status of participants at Shepherd Center is described below in Table 5. No participants have yet been enrolled at Kessler because piloting has begun at Shepherd Center first.

Table 5. Screening and Enrollment Status for Piloting at Shepherd Center

	Clinicians	People with Tetraplegia	Caregivers
Screening Complete ¹	44	42	9
Screening in Process	0	10	0
Eligible	42 ²	19 ⁴	9
Enrolled	16	6	6
Declined	3	0	0
Consent in Process	23 ³	3	3

¹ Clinicians are not formally screened; this is the number approached about the study.

² Two clinicians who were approached were considered ineligible because they were about to transition off the inpatient rehabilitation unit and would no longer see inpatients with tetraplegia.

³ Includes 5 clinicians who have stated interest in participating and who are currently being scheduled for consent and training as well as 18 clinicians who have been informed of the study but have not yet decided whether they wish to participate.

⁴ Includes 9 patients who are eligible and have clinicians on their team who have consented to participate in piloting as well as 10 patients who are eligible based on their injury characteristics but who do not have any clinicians on their team who have consented to participate in piloting. Pilot testing cannot be initiated for these 10 patients until at least one clinician on their team has consented to participate in piloting.

The total number of TEAM Tool assessments completed to date is 26 (9 at admission, 10 at midpoint, 10 at discharge).

Specific Objectives. The specific objectives of the activities discussed above were to identify (1) obtain information needed to develop the assessment tool (TEAM Tool), (2) refine the initial draft of the tool in preparation for piloting, and (3) through piloting, assess the extent to which the TEAM Tool is understandable and useful in clinical care.

Significant Results. The themes discussed above in (3) *Analyze chart review and focus group data to identify themes relevant to the development of the assessment tool* summarize focus group findings that aided the creation of the TEAM Tool. (Additional findings are presented in detail in the annual report for 2015). In addition, we conducted two analyses that focused on the subset of focus group content related to interpersonal relationships between caregivers and directors of care as well as barriers and facilitators to learning to direct one's own care. These results are presented in two abstracts that were accepted for presentation at national conferences. Please see the section on dissemination below and the Appendix for presentation of those findings.

Discussion of Stated Goals Not Met. Recruitment for piloting is progressing slower than expected. While many clinicians have expressed support for the project, a smaller number have committed to participate in piloting. However, we are encouraging those clinicians who have enrolled to speak with others on their care team, which has resulted in additional enrollments. Dr. Zanca has also scheduled a visit to Shepherd Center in October 2016 to obtain feedback from those clinicians already involved in piloting and to educate other clinicians about the project to encourage participation.

What opportunities for training and professional development has the project provided?

Nothing to Report

How were the results disseminated to communities of interest?

An oral presentation titled “Building Positive Working Relationships Between People with SCI and Caregivers” was given at the Academy of Spinal Cord Injury Professionals (ASCIP) Annual Conference and Expo, which was held in Nashville, TN in September 2016. This conference is attended by SCI professionals (therapists, social workers, case managers, nurses, physicians) involved in direct patient care, supervisors and managers of clinical programs, and researchers. The presentation was well attended (approximately 100 participants). Audience members expressed their excitement about efforts to better assess direction of care and caregiving skills, stating that these skills are fundamentally important to successful community living. The abstract submitted to ASCIP appears in the Appendix to this report. In addition, an abstract entitled “Learning to Direct Care After Spinal Cord Injury” was accepted for poster presentation at the American Congress of Rehabilitation Medicine in November 2016. A copy of the abstract is included in the Appendix.

What do you plan to do during the next reporting period to accomplish the goals?

Activities during the next reporting period will include:

- Submitting renewal applications to the local IRBs of participating sites and to HRPO to maintain approval of human subject research activities
- Piloting the tool at Kessler Institute for Rehabilitation and Shepherd Center to identify strengths and weaknesses
- Refine the tool based on feedback obtained during piloting

4. IMPACT

What was the impact on the development of the principal discipline(s) of the project?

The focus groups have produced a rich data set that will make an impact on the field of SCI rehabilitation in several ways:

- *The focus group findings will inform the development of the proposed assessment tool for direction of care and caregiving skills.* Once developed, this tool is anticipated to

help the process of training caregivers and persons with SCI by helping to identify goals for training, improving communication among team members about training status, providing information to third party payers to help justify increased time in rehabilitation for training, and contributing to the conduct of research that will demonstrate linkages between care skills, secondary complications, and quality of life.

- ***Data gathered in the focus groups provide us with a greater understanding of the direction of care/caregiving training process***, including its contents and barriers and facilitators to its success. Focus group participants spoke about the challenges of adjusting to injury and the overwhelming nature of acute rehabilitation immediately following injury. This information will be valuable to leaders of rehabilitation programs to assist their quality improvement efforts and assist them in refining the design of training programs to better accommodate the needs of people with SCI and their families.
- Persons with tetraplegia and their caregivers offered a number of practical suggestions that would be useful to people who are newly injured and their loved ones. These included tips for interviewing personal care attendants, suggestions for how to communicate successfully with caregivers, key signs of potential medical complications, strategies to avoid errors in care (keeping lists, organizing supplies, etc.), among others. This ***information may form the basis of training materials and programs*** to help people who are newly injured and their loved ones be better prepared to direct and/or provide care after discharge.

What was the impact on other disciplines?

Nothing to Report

What was the impact on technology transfer?

Nothing to Report

What was the impact on society beyond science and technology?

Nothing to Report

5. CHANGES/PROBLEMS

Changes in Approach and Reasons for Change

No changes have been made in the scientific approach during the current reporting period.

Actual or Anticipated Problems or Delays and Actions or Plans to Resolve Them

The completion of tasks in the proposed project has been delayed due to several factors, including the prolonged period of time (approximately 9 months) required to complete the processing of the transfer of the grant from Mount Sinai School of Medicine to Kessler

Foundation, family leave taken by Dr. Zanca (which started 8-Jan-2014 and ended on 7- Apr-2014), a vacancy in the Research Assistant position, difficulties accessing a portion of the medical records needed for the project, and a serious illness in Dr. Zanca's family. A prolonged IRB review process at the East Orange VA delayed the completion of focus groups at that site. In addition, a change in the transcription company utilized by the East Orange VA (and the lengthy approval process required before setting up that company as an official vendor) delayed the completion of transcription of the East Orange VA focus groups. Finally, the rate of clinician enrollment for piloting has been slower than expected.

Several strategies have been (or are being) used to mitigate these issues:

- Greater than planned levels of effort were devoted by the project Research Assistant after completion of the transfer of the grant from Mount Sinai to allow faster completion of chart review data collection.
- Dr. Zanca collaborated with medical records staff to identify a work-around for the technical issue that was preventing access to needed records, and was able to obtain the medical chart data required for the project.
- Dr. Zanca worked remotely as circumstances permitted during her family leave and while she was providing care for her mother during her illness. She maintained oversight of project staff by phone and email. Dr. Zanca no longer has the caregiving responsibilities that impeded her progress on the project.
- Analysis of focus group data collected at Kessler and Shepherd Center proceeded in parallel with completion of the focus groups at the East Orange VA to avoid further delays in project implementation.
- Dr. Zanca and Dr. Gill worked with the IRB coordinator at the EOVA IRB to resolve issues with the continuation/modification submission and obtain approval to continue the project.
- Dr. Zanca utilized notes taken during the focus group discussions and the audio recordings of the East Orange focus groups until full transcripts became available.
- An in-person visit has been scheduled for Shepherd Center to engage clinicians and encourage enrollment in the study.
- Clinicians at Shepherd who are already enrolled in the study are speaking with others on their clinical teams to encourage participation.

A request for an Extension Without Funds was submitted in August 2016 to extend the project for an additional year to allow for the completion of piloting.

Changes that had a Significant Impact on Expenditures

Fewer funds have been expended than were expected by this point in the project because (1) human subject research activities were required to be on hold until the grant was officially transferred to Kessler Foundation (2) Dr. Zanca took unpaid family leave in early 2014 and (3) there was a vacancy in the Research Assistant position. We anticipate catching up on expenditures over the course of the coming year as the remaining project activities are completed.

Significant Changes in Use or Care of Human Subjects, Vertebrate Animals, Biohazards, and/or Select Agents

The IRB protocols and consent forms previously approved at Shepherd Center and Kessler Foundation were revised to be more specific about the kinds of data to be collected during piloting, refine language in the informed consent documents for clarity and comprehensiveness, and allow piloting of the tool to begin prior to the completion of the informed consent process to balance the need to collect data early on in the rehabilitation process with the need to provide people with tetraplegia and their caregivers adequate time to consider study participation. In the event that a person with tetraplegia and/or caregiver declines participation, no further assessment tool piloting will occur with those individuals and any data previously collected will be stripped of all identifiers to render it anonymous. Dr. Zanca has been in contact with the HRPO coordinator for the project about these changes, and the approved IRB documents presenting these revisions have been submitted to HRPO. The most recent dates of IRB approval at each site are 6-Oct-2016 for Kessler, 20-Jun-2016 for Shepherd Center, and 13-Jul-2016 for EOVA.

6. PRODUCTS

Several products have been created during the current reporting period:

1. Teaching Effective Assistance Management (TEAM) Tool

The TEAM Tool provides a mechanism for clinicians to systematically evaluate the ability of people with tetraplegia to direct their care and the ability of caregivers to provide appropriate assistance. The tool is currently being pilot-tested in inpatient rehabilitation.

2. TEAM Tool Instruction Guide

The instruction guide describes the purpose and intended use of the TEAM Tool, and provides definitions for terms used in the tool. The guide is used to train clinicians in the use of the tool and to serve as an ongoing reference during piloting.

3. Abstract/Presentation at the 2016 Academy of Spinal Cord Injury Professionals Annual Conference and Expo

A presentation entitled “Building Positive Working Relationships Between People with SCI and Caregivers” was given to share suggestions offered by experienced care directors, caregivers, and clinicians. These suggestions will aid the development of education materials and programs to facilitate more positive care director-caregiver interactions. The abstract associated with this presentation will be published as an abstract in the Journal of Spinal Cord Medicine.

4. Abstract/Presentation at the American Congress of Rehabilitation Medicine (Abstract accepted during the current reporting period, presentation to be given in November 2016)

An abstract entitled “Learning to Direct Care After Spinal Cord Injury” was accepted for poster presentation. This presentation will share barriers and facilitators to developing direction of care

skills, and will be helpful to those in a position to develop programs and materials to facilitate training of people with SCI. The abstract associated with this presentation will be published in Archives of Physical Medicine and Rehabilitation.

7. PARTICIPANTS & OTHER COLLABORATING ORGANIZATIONS

What individuals have worked on the project?

Kessler Foundation

Name:	Jeanne Zanca
Project Role:	Principal Investigator
Nearest Person Month Worked:	4
Contribution to Project:	<ul style="list-style-type: none"> ▪ Obtained and renewed all regulatory approvals for the project ▪ Worked with grants administration offices at all collaborating sites to establish/renew subaward agreements ▪ Worked with collaborators to complete focus group data collection and analyze data ▪ Led creation of TEAM Tool and instruction guide ▪ Facilitated conference calls to obtain feedback on tool and guide ▪ Revised guide in preparation for piloting ▪ Worked with collaborators to initiate piloting

Shepherd Center

Name:	John Morris
Project Role:	Co-Investigator, Local Site Lead Investigator
Nearest Person Month Worked:	1
Contribution to Project:	<ul style="list-style-type: none"> ▪ Obtained and renewed all regulatory approvals for human subjects research activities at Shepherd Center ▪ Oversaw recruitment and consent processes for Shepherd Center participants ▪ Contributed to data analysis ▪ Assisted with preparation of presentations of findings ▪ Collaborated with Dr. Zanca and supervised local staff in initiation of piloting

Name:	Marina Moldavskiy
Project Role:	Clinical Research Coordinator
Nearest Person Month Worked:	4

Contribution to Project:	<ul style="list-style-type: none"> ▪ Recruited participants for piloting at Shepherd Center and obtained informed consent ▪ Assisted with logistical arrangements for clinician training (room reservations, refreshments, subject compensation, etc.) and piloting ▪ Assisted with IRB applications ▪ Maintained study documentation
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Mount Sinai

Name:	Marcel Dijkers
Project Role:	Co-Investigator
Nearest Person Month Worked:	2
Contribution to Project:	<ul style="list-style-type: none"> ▪ Contributed to data analysis ▪ Assisted with preparation of presentations of findings

Has there been a change in the active other support of the PD/PI(s) or senior/key personnel since the last reporting period?

Dr. Zanca has won a grant from the National Institute on Disability and Rehabilitation Research for a project entitled “Improving Quality of Personal Care Assistance Services for People with SCI Through Online Education.” This project was inspired by findings from the focus groups conducted prior to TEAM Tool development, in which frequent turnover of personal care assistants and the need to orient them to the needs of people with SCI were discussed by many participants. Details about this grant award are as follows:

Title: Improving Quality of Personal Care Assistance Services for People with SCI through Online Education

Agency: National Institute on Disability and Rehabilitation Research

Grant Number: 90IF0115-01-00

PI: Jeanne M. Zanca, PhD, MPT

Role: Co-Investigator

FTE: 20% (Years 1 and 3). 25% (Year 2)

Period: 9/30/2016 – 9/29/2019

Total award: \$ 595,724

Objectives: 1) Identify learning needs of personal care assistants (PCAs) through focus groups with key stakeholders, including people with spinal cord injury (SCI) and their families, PCAs, SCI clinicians, and care agency representatives; 2) Create a course curriculum and web-based materials to implement that curriculum; 3) Pilot-test the online course with personal care assistants who are unfamiliar with SCI to create a final version that is suitable for use by the public.

What other organizations were involved as partners?

Organization Name:	East Orange Campus of the VA New Jersey Health Care System
Location of Organization:	East Orange, NJ
Partner's contribution to the project:	Collaboration (e.g., partner's staff work with project staff on the project)

Organization Name:	Icahn School of Medicine at Mount Sinai
Location of Organization:	New York, NY
Partner's contribution to the project:	Collaboration (e.g., partner's staff work with project staff on the project)

Organization Name:	Shepherd Center
Location of Organization:	Atlanta, GA
Partner's contribution to the project:	Collaboration (e.g., partner's staff work with project staff on the project)

8. SPECIAL REPORTING REQUIREMENTS

Not Applicable

9. APPENDICES

The following appendices are included with this report:

- (1) Updated Quad Chart
- (2) Teaching Effective Assistance Management (TEAM) Tool (piloting version)
- (3) TEAM Tool Instruction Guide (piloting version)
- (4) Abstract accepted for presentation at the Academy of Spinal Cord Injury Professionals Educational Conference and Expo
- (5) Slides from presentation given at the Academy of Spinal Cord Injury Professionals
- (6) Abstract accepted for presentation at the American Congress of Rehabilitation Medicine Annual Conference
- (7) Copy of poster to be presented in November 2016 at the American Congress of Rehabilitation Medicine Annual Conference

APPENDICES

Systematic Assessment of Caregiving Skill Performance by Individuals with Tetraplegia and Their Caregivers

Log #: SC110247 Award # W81XWH-12-1-0553

PI: Jeanne M. Zanca, PhD, MPT Org: Kessler Foundation (after transfer from Mount Sinai School of Medicine) Award Amount: \$618,139



Study/Product Aim(s)

- (1) Identify care-direction and caregiving skills and criteria for evaluating those skills that are meaningful to SCI clinicians, people with tetraplegia (PWTs), and their caregivers.
- (2) Create an assessment tool that reflects these goals/indicators/criteria.
- (3) Assess the comprehensiveness and utility of the tool in inpatient rehabilitation.
- (4) Create a refined version of the assessment tool suitable for further development and evaluation in subsequent research.

Approach

Chart reviews and focus groups will be used to identify relevant content for the assessment tool; the tool will be drafted with feedback from PWTs, caregivers, and clinicians; pilot-testing in rehabilitation will done to refine the assessment tool for further testing in future studies

Improved assessment of skills over time

Better planning and evaluation of training

Improved skill acquisition by PWTs and caregivers

Fewer complications and better quality of life

Figure: Projected impacts of project on people with tetraplegia and their caregivers. Accomplishment: 8 chart review, 67 focus group, and 28 piloting participants enrolled; two abstracts accepted for presentation; 26 Assessments completed

Timeline* and Cost

Activities	FY 14	FY 15	FY 16-17
Identify relevant content for instrument via chart review, focus groups, interviews			
Create initial version of assessment instrument			
Pilot-test the instrument in inpatient rehabilitation			
Estimated Budget (\$618,139)	236,124	173,884	208,131

Updated: 29-Oct-2016

* EWOFF request approved

Goals/Milestones

CY14/15/16 Milestones—Focus groups complete; “TEAM Tool”/instructions created; Two abstracts discussing findings accepted for presentation; 28 piloting participants enrolled; 26 assessments completed

CY16/17 Goals –

- Pilot assessment tool and revise based on feedback received
- Continue dissemination of project findings through presentations at professional meetings; Initiate publications that present the assessment tool and share study participants’ insights on the process of learning to direct/provide care and creating and maintaining healthy interpersonal dynamics between care directors and caregivers

Comments/Challenges/Issues/Concerns

- Timeline delayed due to grant transfer, vacancy in staff, medical record access issues, leave, complexities in tool development and enrollment

Budget Expenditure to Date (see Challenges for explanation of delay)

Projected Expenditure: >\$618,000 Actual Expenditure: \$376,163 (through 30-Sep-2016)

Clinician ID: _____

Assessment Date: _____

TASKS – Part A		Care Director		& Caregiver		= Team	
		ID: _____ Safety	Problem-Solving	ID: _____ Safety	Problem-Solving	Safety	Problem-Solving
Preventing Complications (Domain 1)		N/A					
	Maintaining Breathing <input type="checkbox"/>						
	Managing Blood Pressure <input type="checkbox"/>						
	Responding to Autonomic Dysreflexia <input type="checkbox"/>						
	Properly Cleaning and Caring for Skin <input type="checkbox"/>						
	Detecting/Responding to Signs of Skin Problems <input type="checkbox"/>						
	Emptying Bowels Regularly <input type="checkbox"/>						
	Emptying Bladder Regularly <input type="checkbox"/>						
	Using Medications as Prescribed <input type="checkbox"/>						
	Taking Precautions Against Infection <input type="checkbox"/>						
	Proper Body Positioning in Bed <input type="checkbox"/>						
	Proper Body Positioning in Wheelchair <input type="checkbox"/>						
	Performing Range of Motion <input type="checkbox"/>						
	_____ (Other)						
	Sum of scores for this domain ÷ # of tasks scored	____ ÷ ____	____ ÷ ____	____ ÷ ____	____ ÷ ____	____ ÷ ____	____ ÷ ____
	= PREVENTING COMPLICATIONS SCORE						
Mobility in Daily Life (Domain 2)							
	Transfers Between Level Surfaces <input type="checkbox"/>						
	Transfers Between Uneven Surfaces <input type="checkbox"/>						
	Emergency Transfers <input type="checkbox"/>						
	Moving Around in Bed <input type="checkbox"/>						
	Mobility (Walking or Wheelchair) on Flat Surfaces <input type="checkbox"/>						
	Mobility (Walking or Wheelchair) on Uneven Surfaces <input type="checkbox"/>						
	Managing Wheelchair Parts <input type="checkbox"/>						
	_____ (Other)						
	Sum of scores for this domain ÷ # of tasks scored	____ ÷ ____	____ ÷ ____	____ ÷ ____	____ ÷ ____	____ ÷ ____	____ ÷ ____
	= MOBILITY SCORE						
Other Daily Activities (Domain 3)							
	Eating and Drinking <input type="checkbox"/>						
	Bathing <input type="checkbox"/>						
	Grooming <input type="checkbox"/>						
	Dressing <input type="checkbox"/>						
	_____ (Other)						
	Sum of scores for this domain ÷ # of tasks scored	____ ÷ ____	____ ÷ ____	____ ÷ ____	____ ÷ ____	____ ÷ ____	____ ÷ ____
	= OTHER DAILY ACTIVITIES SCORE						
	Sum of task scores in domains 1-3 ÷ # tasks scored	____ ÷ ____	____ ÷ ____	____ ÷ ____	____ ÷ ____	____ ÷ ____	____ ÷ ____
	= OVERALL SCORE for Part A						

Clinician ID: _____

Assessment Date: _____

TASKS – Part B		Care Director	& Caregiver	= Team
		ID: _____	ID: _____	
		Communication	Communication	Communication
Communicating Effectively (Domain 4)	N/A			
Using Appropriate Language	<input type="checkbox"/>			
Using Appropriate Tone of Voice	<input type="checkbox"/>			
Detecting/Responding to Misunderstanding or Uncertainty	<input type="checkbox"/>			
Rephrasing or Changing Instructions When Needed	<input type="checkbox"/>			
Speaking Up for Needs or Concerns	<input type="checkbox"/>			
Providing Helpful Feedback	<input type="checkbox"/>			
Being an Active Listener	<input type="checkbox"/>			
_____ (Other)				
Sum of scores for this domain ÷ # of tasks scored		____ ÷ ____	____ ÷ ____	____ ÷ ____
= COMMUNICATION SCORE (OVERALL SCORE Part B)				

Scale Definitions and Scoring Criteria for Parts A and C:

For each scale, select the score that best reflects the abilities of the person (care director or caregiver) or team (care director and caregiver working together), considering all behaviors observed over the **past week**. If performance varied during this period, select the score that best represents the **CURRENT** abilities of the care director, caregiver, or team. Mark "N/A" if a task does not require assistance from a caregiver or is not medically or functionally relevant to the person with tetraplegia.

Safety Scale: Addresses ability to direct or perform a care task in a manner that prevents illness or injury (physical, emotional, or financial) to the person receiving assistance or his/her caregiver.

Safety Scoring: How much of the care direction/caregiving is performed safely *without assistance* from the trainer?

1. None – Requires assistance from the trainer to direct or perform all of this task safely
2. Some – Able to direct or perform some of this task safely without assistance from trainer
3. Most – Able to direct or perform most of this task safely without assistance from trainer
4. All – Able to direct or perform all of this task safely without assistance from the trainer

Problem-Solving Scale: Relates to the ability to adjust how a task is directed or performed in response to unusual or challenging circumstances to maintain safety and/or increase efficiency.

Problem-Solving Scoring: How much of the problem-solving process can be done *without assistance* from the trainer?

1. None – Requires complete assistance from trainer to identify problems and implement solutions
2. Some – Able to identify problems, requires assistance from trainer to identify and implement solutions
3. Most – Able to identify both problems and appropriate solutions but requires assistance from trainer to implement solutions
4. All – Able to identify problems and appropriate solutions, and can implement solutions without assistance from trainer

Scoring Criteria for Part B:

Communication Scale: Relates to the ability of the care director and caregiver to communicate effectively and appropriately with one another.

Communication Scoring: How much of the time is communication occurring in an *appropriate manner without assistance* from the trainer?

1. None – Unable to communicate effectively without assistance from trainer
2. Some – Able to communicate effectively *some* of the time without assistance from trainer
3. Most – Able to communicate effectively *most* of the time without assistance from trainer
4. All – Able to communicate effectively *all* of the time without assistance from trainer

Clinician ID: _____

Assessment Date: _____

TASKS – Part C

N/A

Home and Community Living (Domain 5)Child Care (if applicable) ☐Pet Care (if applicable) ☐Maintaining a Clean and Healthy Home Environment ☐Food Preparation ☐Phone and Computer Access ☐Managing Legal/Financial Documents & Affairs ☐Maintaining Stock of Supplies ☐Maintaining Equipment ☐Transportation and Travel Planning ☐Work, School, or Leisure Activities ☐Performing Exercises for Strength or Fitness ☐Facilitating Intimate Relationships ☐Accessing Resources When Needed ☐

_____(Other)

Sum of scores for this domain ÷ # of tasks scored

= HOME/COMMUNITY SCORE

Managing Personnel (Domain 6)Recruiting and Interviewing ☐Establishing Expectations and Policies ☐Coordinating Coverage and Schedules ☐Transitioning to New Staff as Needed ☐

_____(Other)

Sum of scores for this domain ÷ # of tasks scored

= MANAGEMENT SCORE

Sum of task scores in domains 5-6 ÷ # tasks scored

= OVERALL SCORE for Part C

Care Director**& Caregiver****= Team**

ID: _____

Safety

Problem-Solving

ID: _____

Safety

Problem-Solving

Safety

Problem-Solving

_____ ÷ _____

_____ ÷ _____

_____ ÷ _____

_____ ÷ _____

_____ ÷ _____

_____ ÷ _____

Share your feedback!

Please use the space below to note general comments or any difficulties you encountered in using the TEAM Tool. These could include difficulties deciding on a score, tasks that are not listed, areas where more guidance or clarity is needed in the instructions, etc. Feel free to share ANY ideas you may have for improving the content, format, or use of the TEAM Tool itself or the Instruction Manual.

For questions about the TEAM Tool or the study in general, please contact:

Marina Moldavskiy
Exercise Specialist, Clinical Research Coordinator
The Virginia C. Crawford Research Institute at Shepherd Center

Thank you for completing this form.

Please return it to the designated location for collection by the study team.

***Teaching Effective Assistance Management
(TEAM) Tool***

Instruction Manual

Version Date 8/17/2016



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1. Overview of the TEAM Tool

The TEAM Tool provides information on the ability of people with tetraplegia due to spinal cord injury to appropriately direct their care and on the ability of caregivers to provide appropriate assistance. The TEAM Tool is completed based on observations of behavior that rehabilitation experts make in the process of training people with tetraplegia and their caregivers in direction of care and caregiving skills.

The TEAM Tool is designed to provide a comprehensive, high-level view of direction of care and caregiving ability. It is intended to complement, not replace, existing medical record documentation and other outcome measures that discuss the functional status of the person with tetraplegia or describe the specific content of training.

2. Background

Depending on the severity of the injury, people with tetraplegia due to spinal cord injury may require help from others to complete daily activities such as washing, moving from bed to chair, preparing food, and other important tasks. Appropriate assistance is critical to enable people with tetraplegia to participate in life activities and to prevent many of the health complications that can result from tetraplegia, such as pressure injury, pneumonia, and urinary tract infections.

Family members are often involved in providing care to people with tetraplegia. People with tetraplegia may also receive care from paid caregivers who are not nurses or otherwise formally trained in how to care for someone with tetraplegia. In order for people with tetraplegia to get the best possible care at home (rather than having to stay in a hospital or nursing home) it is important that they be able to tell someone when they need care and what needs to be done to help them (referred to as “direction of care”). It is also important that family members or others who are providing care to someone with tetraplegia learn how to properly perform these care tasks.

The process of learning to direct and provide care usually begins in acute inpatient rehabilitation. Clinicians and other rehabilitation professionals provide instruction about SCI and its consequences as well as hands-on training in directing care and providing assistance in tasks such as bowel and bladder care, transfers, bathing, range-of-motion exercises, and other activities. Ideally, people with tetraplegia and their caregivers are offered opportunities to practice directing and providing care, and receive feedback from rehabilitation professionals on their performance. Learning direction of care and caregiving skills continues after discharge as people with tetraplegia and their families continue rehabilitation in an outpatient setting and gain experience in the community.

While training in direction of care and caregiving is an important part of inpatient rehabilitation, current assessment tools and outcome measures provide no information on these skills. Commonly-used tools such as the Functional Independence Measure provide scores that are based on the level of independence of the person with tetraplegia. For skills that pertain to physical activity, such as transfers, these tools do not differentiate individuals who are actively engaged and in control of the task via verbal direction from those that are not participating in any way. Similarly, the quality of the assistance provided by the caregiver is not considered in the scoring of these tools. As a result, the rehabilitation field does not have a systematic (well-defined and consistent) way of describing how well someone can direct or provide care.

3. Anticipated Benefits of Using the TEAM Tool

The TEAM Tool is expected to enhance rehabilitation care by:

- Helping to identify training goals
- Documenting improvements in direction of care and caregiving skills over time, to provide justification for ongoing rehabilitation and to build confidence among those being trained
- Promoting conversations about difficult subjects such as care needs, willingness and ability of loved ones to provide care, interpersonal dynamics, etc.
- Facilitating discharge planning by helping clinicians assess and discuss readiness for discharge, identify areas in need of further training to prepare for discharge, etc.

The TEAM Tool is expected to enhance program evaluation and research by:

- Demonstrating the extent to which training programs improve direction of care and caregiving skills
- Facilitating assessment of relationships between direction of care/caregiving ability and important outcomes (such as complications, rehospitalizations, cost of care, and well-being)

4. Key Terms

Care director typically refers to the person with tetraplegia who is being trained to verbally instruct others in how to provide assistance. In cases where a person with tetraplegia is not being trained to direct care due to severe cognitive impairments or other issues, a family member or other responsible party may be trained to direct other caregivers (such as hired aides). In such cases, the responsible party is considered the care director.

Caregiver refers to a person who is being trained to provide assistance to the person with tetraplegia. The term “caregiver” is used in a broad sense, and may refer to paid or unpaid caregivers, including family members, friends, or staff that is hired privately or provided through an agency.

Team refers to the care director and caregiver working together as a unit. Because the dynamics between specific people are unique, each combination of care director and caregiver is its own “team.”

Trainer refers to a clinician, rehabilitation professional, or other “expert” (such as an experienced peer educator) who provides training in direction of care and caregiving skills in a rehabilitation context.

Task refers to an activity or (more commonly) a set of activities related to a particular objective (such as proper body positioning) or area of functioning (such as eating and drinking). Each person with tetraplegia has a unique combination of needs and preferences. Therefore, the specific tasks to be performed will vary from person to person. Other forms of documentation, such as the medical record or checklists for caregivers, can provide detail on the specific tasks to be performed for a particular person with tetraplegia. The types of activities included in each task (the “scope” of the task) is defined in Section 6 below.

Scale refers to a way of “measuring” a particular aspect of care direction and/or caregiving performance. The TEAM Tool includes three scales: *Safety*, *Problem-Solving*, and *Communication*. Because these scales represent distinct concepts, scores are calculated separately for each scale using different scoring criteria.

Domain refers to a collection of tasks that relate to a larger goal or activity. The TEAM Tool provides information on six domains: Preventing Complications, Mobility in Daily Life, Other Daily Activities, Communicating Effectively, Home and Community Living, and Managing Personnel.

Domain Score refers to a score that is calculated within a particular domain, based on scores for all applicable tasks within that domain. Domain Scores are calculated separately for the Safety, Problem-Solving, and Communication scales.

Overall Score is calculated for each part (A, B, C) of the TEAM tool based on *all* the scores recorded for the tasks listed within a particular part (A, B, or C) of the form. Overall scores are calculated separately for the Safety, Problem-Solving, and Communication scales.

5. Structure of the TEAM Tool

Listing of Tasks

The TEAM Tool consists of three parts, organized by the nature of the tasks included in each part.

- **Part A** focuses on tasks that are fundamental to health and/or everyday functioning for which direction of care/caregiving training typically begins in an inpatient setting.
- **Part B** addresses communication-related behaviors that are observed by trainers as people with tetraplegia and their caregivers practice direction of care or providing care during training.
- **Part C** addresses more advanced skills related to maintaining one’s home, participating in community activities, and managing hired staff (if applicable). The tasks in Part C are included because they are considered important to people with tetraplegia and are needed for success in community life on the long-term. However, depending on the care setting, these areas may not be addressed in inpatient rehabilitation. Training may occur in outpatient rehabilitation in the context of other programs offered post-discharge. These advanced skills are therefore placed in a separate section of the TEAM Tool, but may be scored by inpatient trainers if they are addressed in training.

Separate Scoring for Care Director, Caregiver, and Team

Within each part of the TEAM Tool, scores are given separately for the care director, caregiver, and for the team (care director and caregiver working together). This approach to score assignment is designed to reflect that the success of a caregiving experience involves contributions from both members of the care team, who may differ in their levels of ability. This approach also provides flexibility, allowing the TEAM Tool to be utilized with the person with tetraplegia who is receiving training even if the caregiver has not yet been identified or is unable to attend training.

6. Scope of Tasks

For all domains, an “other” field is available on the form to provide trainers the option of adding another task that is relevant to the person with tetraplegia but is not already listed.

Part A

Domain 1. Preventing Complications

1. **Maintaining Breathing.** Includes ability to keep ventilator fully powered, properly maintained, and functioning at the correct settings as well as implementing emergency measures in case of a ventilator failure (including using manual bagging to maintain breathing and contacting appropriate people for help). Also includes suctioning, assisted coughs, tracheostomy care, adherence to swallowing-related precautions, and other measures taken to prevent secretions or food/liquids from interfering with breathing. May include use of supplemental oxygen if prescribed.
2. **Managing Blood Pressure.** Includes any actions taken to prevent a problematic drop or increase in blood pressure. Such actions may include use of stockings, abdominal binders, or other aids to help maintain pressure; medications to manage blood pressure; care with position changes to avoid sudden drop in blood pressure, and other actions.
3. **Responding to Autonomic Dysreflexia.** Includes recognizing signs of autonomic dysreflexia, taking actions to stop the dysreflexia (sitting up, emptying bladder, loosening clothing, using medication, etc.), and seeking emergency assistance if needed.
4. **Properly Cleaning and Caring for Skin.** Includes appropriate cleaning/rinsing of skin via a shower or bed bath, thoroughly drying the skin, applying lotion, handling the skin gently to avoid irritation or damage, and other actions needed to ensure skin remains clean, dry, and free of injury.
5. **Detecting/Responding to Signs of Skin Problems.** Includes inspecting skin in a manner that would allow signs of skin damage to be seen (such as using appropriate lighting, looking at all areas at risk), identifying areas that suggest a problem may be developing (such as pressure injury), and identifying appropriate actions to take to respond to what is found during inspection (adjusting sitting time or frequency of repositioning, contacting physician, etc.).
6. **Emptying Bowels Regularly.** Includes implementation of the prescribed bowel program. This includes use of medications or supplements, enemas or mini-enemas, suppositories, stimulation with one’s finger or a device, and other actions required so that all stool is removed from the bowel. Also includes correct assessment of when bowels are empty and performance of bowel emptying techniques with appropriate hand hygiene/glove use, and in a manner that reduces the likelihood of injuring the anus, rectum, or other bowel structures. May include proper colostomy use if

applicable. Also includes ability to identify when a bowel problem may require further intervention by a physician or other health care professional.

7. Emptying Bladder Regularly. Includes implementation of all actions required to ensure that the bladder is emptied completely and regularly. Includes proper hand hygiene, glove use, cleansing of skin in the areas where bladder emptying is occurring, and handling of supplies to prevent infection. Also includes correct use of bladder medications, catheters, physical techniques to induce urination (such as applying pressure), as prescribed. Also includes ability to identify when intervention by a physician or other health care professional may be required to address a possible infection or other issue (as indicated by the amount, odor, color, cloudiness of urine).
8. Using Medications as Prescribed. Pertains to taking medications at appropriate times and dosages, including ability to identify potential side effects and take action to follow-up on medication-related issues.
9. Taking Precautions Against Infection. Includes actions taken to avoid infection in any part of the body. Includes proper hand hygiene, cleaning or sanitizing of equipment that could spread infection (such as leg bags), appropriate handling and storage of equipment, etc. *Note: This task may overlap with others where proper execution of the task includes steps to prevent infection (such as maintaining breathing, emptying bladder regularly). Behaviors that relate both to infection control and to the performance of another task may be considered in the scoring of both tasks.*
10. Proper Body Positioning in Bed. Includes both static positioning in bed and turning techniques. May include supporting shoulders to avoid dislocation, preserving tightness in hands when needed for grasping objects (tenodesis), positioning body to avoid excessive pressure, ensuring ability to reach bed controls independently (if applicable), using splints or other devices to help hold the body in the correct position, and other actions required to keep the person with tetraplegia's body in a position that prevents complications (including pain, skin damage, range of motion problems, falls) and maximizes their ability to function.
11. Proper Body Positioning in Wheelchair. Includes both static sitting and weight-shifting techniques. May include supporting shoulders to avoid dislocation, preserving tightness in hands when needed for grasping objects (tenodesis), positioning body to avoid excessive pressure, ensuring ability to reach wheelchair controls independently (if applicable), using splints or other devices to help hold the body in the correct position, and other actions required to keep the person with tetraplegia's body in a position that prevents complications (including pain, skin damage, range of motion problems, falls) and maximizes their ability to function.
12. Performing Range of Motion. Includes performance of exercises to prevent loss of motion in arms, legs, hands, or other body parts. Technique of moving and monitoring for signs of problems (such as grimacing, increase spasticity, etc.) may be considered in scoring.

Domain 2. Mobility in Daily Life

13. Transfers Between Level Surfaces.^{*} Includes all aspects of directing/performing transfers *between surfaces that are level*. Typically includes transfers between bed, wheelchair, and commode/shower chair, as long as both transfer surfaces are level with one another. Includes appropriate use of

equipment, appropriate set-up of the surfaces involved in the transfer, receiving/providing assistance as needed to perform the transfer and avoid a fall, etc.

14. Transfers Between Uneven Surfaces.^{*} Includes all aspects of directing/performing transfers *between surfaces that are uneven (not level with one another)*. Includes car transfers but excludes floor to chair transfers, which are covered under Emergency Transfers below). May include transfers between other surfaces (bed, wheelchair, commode/shower chair) if the transfer surfaces are not level with one another.

* When determining whether to score a particular transfer as part of Transfers Between Level Surfaces or Transfers Between Uneven Surfaces, remember that the key element is the “level-ness” of the transfer, not the types of surfaces involved (bed, wheelchair, shower chair, etc.). When in doubt, include a transfer you consider to be more difficult under Uneven Surfaces rather than Level Surfaces.

15. Emergency Transfers. Pertains to transfers that may be needed in case of emergency, such as getting up from the floor or getting out of the chair quickly in case of malfunction or emergency requiring evacuation outside of the chair.
16. Moving Around in Bed. Includes receiving/providing appropriate assistance to move from sitting to supine (laying), rolling, scooting, etc.
17. Mobility (Walking or Wheelchair) on Flat Surfaces. Includes receiving/providing appropriate assistance to move (via wheelchair or walking) over level surfaces. Typically includes interior floors but may also include paved outdoor surfaces if they are smooth. Includes guarding techniques, cueing or assistance for maneuvers in tight spaces, use of manual mode for power chair users.
18. Mobility (Walking or Wheelchair) on Uneven Surfaces. Includes receiving/providing appropriate assistance to move (via wheelchair or walking) over uneven surfaces, such as grass, ramps, wheelchair lifts, curbs, stairs (as applicable to the person receiving assistance). Includes guarding techniques, cueing or assistance to maneuver in tight spaces, use of manual mode for power chair users.
19. Managing Wheelchair Parts. Includes manipulating parts of the wheelchair to allow for transfers, wheeling or driving the chair, storage or transport of the chair. Includes moving and positioning armrests, footrests, headrest, drive control, or other parts. For manual wheelchair users, includes removing and replacing wheels and folding the chair (if applicable). For power wheelchair users, includes charging the chair but excludes driving it into a vehicle (which would be considered part of Walking or Wheeling on Uneven Surfaces above).

Domain 3. Other Daily Activities

20. Eating and Drinking. Includes directing a caregiver and/or providing assistance in bringing food and drink to the mouth. Excludes cooking and food selection. Includes positioning the person with tetraplegia appropriately (to prevent food going into the airway, enable him/her to hold/reach utensils, cups, etc.), providing food in appropriate bite sizes and at an appropriate rate, etc.

21. Bathing. Includes directing a caregiver or providing assistance in washing body and hair via shower, bed bath, or other means. Excludes transfers involved in bathing, which are covered under either Transfers Between Level Surfaces or Transfers Between Uneven Surfaces depending on the setup.
22. Grooming. Includes washing face and hands, brushing and flossing of teeth, shaving, styling hair and (if applicable) applying makeup in the manner preferred by the person receiving assistance.
23. Dressing. Includes dressing of the upper and lower body in a manner that avoids complications (as might occur from clothing or shoes that are too tight) and achieves the appearance desired by the person receiving assistance.

Part B

Domain 4. Communicating Effectively

24. Using Appropriate Language. Includes addressing the other member of the care team (care director or caregiver) using their preferred title or name, expressing gratitude, avoiding negative words or insults.
25. Using Appropriate Tone of Voice. Includes speaking at a volume and pace that is conducive to understanding, using a tone that is appropriate to the situation. Also includes non-verbal aspects of communication, such as eye contact, smiling (when appropriate), avoiding negative gestures or actions (sighs, groans, eye-rolling, etc.)
26. Detecting/Responding to Misunderstanding or Uncertainty. Includes ability to recognize when the other member of care team is uncertain about what to do or may have misunderstood what has been said and then taking appropriate actions to clarify what is needed. Signs of misunderstanding may include hesitance in speaking or performing a task, or actions or gestures (such as furrowed brow, sighs, groans, frown, unusual silence, etc.). Indicators that the care director or caregiver is appropriately detecting and responding to uncertainty include confirming an instruction or request, adding clarification, asking if additional or different instructions would be helpful, etc.
27. Rephrasing or Changing Instructions When Needed. Includes ability to use different words or other techniques (such as demonstration--when feasible, reference to a document, picture, or video, etc.) to help the other member of the care team understand what is being said or requested.
28. Speaking up for Needs or Concerns. Includes the extent to which members of the team speak up when they have a question or concern, rather than allowing someone else to speak for them or not speaking until after a problem occurs.
29. Providing Helpful Feedback. Includes telling the other member of the care team what worked well and what did not in the care interaction, using language that is respectful and non-accusatory in tone.
30. Being an Active Listener. Includes behaviors such as making eye contact, allowing the speaker to speak without interruptions (except when needed to clarify what is being said), restating what was said to make sure it was understood, etc.

Part C**Domain 5. Home and Community Living**

31. Child Care. Includes directing/providing assistance with addressing the child's basic needs (bathing, food, clothing, diapering, toileting) as well as participating in activities together (games, homework, etc.)
32. Pet Care. Includes directing/providing assistance with addressing the pet's basic needs (feeding, taking care of waste, cleaning/grooming, other aspects of maintaining the health and well-being of a pet), as well as participating in activities together.
33. Maintaining a Clean and Healthy Home Environment. Includes assistance related to house cleaning as well as laundry.
34. Food Preparation. Includes assistance with shopping, meal planning, cooking, storage/packaging of food, etc.
35. Phone and Computer Access. Includes directing/providing assistance with use of a telephone (land-line or cellular), tablet, laptop computer, desktop computer, or other electronic device used for communication, information access, control of environment, or other purposes. *Note: This task may overlap with others that involve phone or computer use, such as Work, School, or Leisure Activities. Behaviors that relate both to phone/computer use and to the performance of another task may be considered in the scoring of both tasks.*
36. Managing Legal/Financial Documents and Affairs. Includes directing/providing assistance with handling of mail, bills, banking, and other affairs.
37. Maintaining Stock of Supplies. Includes directing/providing assistance with inventory of medical and household supplies, ordering, and organization of supplies once received.
38. Maintaining Equipment. Includes directing/providing assistance with inspecting equipment (wheelchairs, cushions, shower chair, commode, mattress, etc.) for signs of wear and tear or malfunction, cleaning equipment (to maintain its appearance and/or function), making arrangements for routine checks or repairs by technicians when appropriate.
39. Transportation and Travel Planning. Includes directing/providing assistance with packing appropriate supplies, verifying accessibility of transportation and lodging, managing time to ensure on-time arrival, etc.
40. Work, School, or Leisure Activities. Includes directing/providing assistance with activities specifically related to taking classes, performing job functions, participating in recreational activities, etc.
41. Performing Exercises for Strength or Fitness. Includes proper performance of recommended home exercises such as functional electrical stimulation cycling, strengthening exercises, etc.

- 42. Facilitating Intimate Relationships. Includes working with a caregiver to prepare for sexual activities, including appropriate positioning, adjustment of catheters or other equipment, contraceptive use, etc.
- 43. Accessing Resources When Needed. Includes recognizing when outside assistance may be needed (from equipment supplier, clinician, other members of support system), working with caregivers to identify an appropriate source of assistance and the best way of contacting that source, and effectively communicating with that resource to obtain the needed assistance.

Domain 6. Managing Personnel

Note: Tasks in this section apply only to those who be using the services of hired caregivers. Only the care director's performance is scored in this section.

- 44. Recruiting and Interviewing. Includes advertising for help, scheduling interviews, conducting interviews.
- 45. Establishing Expectations and Policies. Includes describing care needs, setting rules of conduct, etc.
- 46. Coordinating Coverage and Schedules. Includes setting schedule for caregivers and communicating that to others as needed; identifying backup plan in case of staff illness or other issue.
- 47. Transitioning to New Staff as Needed. Includes communicating intent to terminate work relationship, preparation of documents, etc.

7. Scoring Criteria

Scores are given for care directors, caregivers, and the care team for three different scales: Safety, Problem-Solving (Parts A and C only), and Communication (Part B only). These scales reflect different aspects of direction of care or caregiving performance. The scores for each scale reflect the extent to which the care director, caregiver, or team are able to appropriately execute that aspect of task performance without assistance from the trainer. Assistance may include physical help, cueing or reminders given via words or gestures, responding to questions asked by the care director or caregiver, or other forms of help. Descriptions of each scale and their scoring criteria are given below:

Safety Scale: Addresses ability to direct or perform a care task in a manner that prevents illness or injury (physical, emotional, or financial) to the person receiving assistance or his/her caregiver.

Safety Scoring: How much of the care direction/caregiving is performed safely *without assistance* from the trainer?

1. None – Requires assistance from the trainer to direct or perform all of this task safely
2. Some – Able to direct or perform *some* of this task safely without assistance from trainer
3. Most – Able to direct or perform *most* of this task safely without assistance from trainer
4. All – Able to direct or perform *all* of this task safely without assistance from the trainer

Problem-Solving Scale: Relates to the ability to adjust how a task is directed or performed in response to unusual or challenging circumstances to maintain safety and/or increase efficiency.

Problem-Solving Scoring: How much of the problem-solving process can be done *without assistance* from the trainer?

1. None – Requires complete assistance from trainer to identify problems and implement solutions
2. Some – Able to identify problems, requires assistance from trainer to identify and implement solutions
3. Most – Able to identify both problems and appropriate solutions but requires assistance from trainer to implement solutions
4. All – Able to identify problems and appropriate solutions, and can implement solutions without assistance from trainer

Communication Scale: Relates to the ability of the care director and caregiver to communicate effectively and appropriately with one another.

Communication Scoring: How much of the time is communication occurring effectively *without assistance* from the trainer?

1. None – Unable to communicate effectively without assistance from trainer
2. Some – Able to communicate effectively *some* of the time without assistance from trainer
3. Most – Able to communicate effectively *most* of the time without assistance from trainer
4. All – Able to communicate effectively *all* of the time without assistance from trainer

Note that “None” and “All” should be interpreted as “nearly none” and “nearly all.” A score of “None” may still be given if a task is done without help but only on rare occasions. Similarly, a score of “All” may

still be given if occasional errors are made but are self-corrected (therefore not requiring assistance) or if assistance is needed on rare occasions or when there are very unusual circumstances.

There is not a strict percentage associated with “some” or “most”—we leave it to the judgment of the trainer to determine which score best characterizes the ability of the care director, caregiver and or team being scored.

8. General Principles for Completing the TEAM Tool

Scores are based on observations of care director and caregiver behavior made by the trainer(s) during training. The TEAM Tool is designed to be completed by rehabilitation professionals (or other “trainers” as defined above) based on observations that they make during the process of training people with tetraplegia to direct their care and training family members or others to perform care tasks (such as assisting with a transfer or catheterization). Scores should be based on behaviors observed during practice of direction of care or caregiving whenever possible, to the extent that practice of these tasks occurs in typical clinical care.

For those tasks that are not feasible to practice in clinical care (such as responding to autonomic dysreflexia) an assessment may be made via a discussion of how the person with tetraplegia would direct the task or how his/her caregiver would perform the task. (It is anticipated that most of the tasks in Part C, which involves community skills and personnel management, will need to be assessed in this manner.)

It is not necessary for the person with tetraplegia AND his/her caregiver to be present for an assessment to take place—in the event that a caregiver is not present or available, a rehabilitation staff member may serve as the caregiver, with direction of care provided by the person with tetraplegia.

Scores are only given for tasks that *involve the assistance of a caregiver*. The TEAM Tool is designed to provide information about direction of care and caregiving ability. Any task that the person with tetraplegia is able to do on his/her own (or is being trained to do on his/her own) should not be scored.

For example, a person with tetraplegia may be trained to drive a power wheelchair over flat surfaces. If the goal of training is for the person with tetraplegia to be able to perform this task without any assistance (supervision, cueing or physical assistance) from a caregiver, then this task should be marked “Not applicable” and should not be scored in the TEAM Tool.

If however, the expectation is that the person with tetraplegia will utilize supervision, cueing, or other assistance from a caregiver for power wheelchair driving over level surfaces post-discharge, this task should be scored.

No changes in typical clinical care are required for the TEAM Tool to be completed. The TEAM Tool is intended to assist the process of training people with tetraplegia and their caregiver by encouraging evaluation of these skills by the rehabilitation team, and providing a mechanism for documenting and communicating assessment findings. The TEAM Tool may “inspire” changes to the training process by drawing attention to areas in which training is needed, but changes in typical care are NOT required for the team tool to be completed.

Decisions about what skills to train, how to train them and when to provide training should be driven by clinical considerations and not by the need to complete the tool. Clinicians may choose to incorporate

the tool in their training efforts in whatever ways feel most appropriate, including reviewing it with patients/caregivers during training, discussing with other members of the patient's clinical team, etc.

Any trainer may score performance in any task that he/she observes. While the scope of practice differs among clinical disciplines (occupational therapy, physical therapy, nursing, etc.), there is often overlap between disciplines in the topics of training. For example, both nurses and occupational therapists may provide education related to intermittent catheterization. For purposes of pilot-testing, any trainer may score any task that is considered part of his/her training activities, regardless of his/her clinical discipline.

Scores are based on observations made during a one week look back period. Scores given on the TEAM Tool are based on observations of behavior made in the week prior to (and including) the date the trainer is completing the tool. A look back period of this length is provided to maximize opportunities to observe various skills, since it is rarely feasible to observe all skills in a single day or even over 2-3 days. It also gives trainers flexibility to complete the tool when their schedules permit.

Scores should be given based on the trainer's assessment of the CURRENT abilities of the care director or caregiver. For tasks that are performed multiple times during the look back period, performance may vary over the course of the week. The trainer should pick the score that he/she feels best reflects the abilities of the care director or caregiver as of the date the TEAM Tool is being completed.

For example, in a situation where performance improved over the course of the week, and less help was needed from the trainer, the score given on the TEAM Tool should be based on the more recent observations.

In other situations, performance may be inconsistent, such that lot of help from the trainer is needed on some days and little on others, with no discernable trend of improvement. In such a case, it may be more appropriate to give a score that reflects the poorer performance, even if little help was needed at the most recent observation. If inconsistency of performance is related to task setup (an "idealized" setup vs. one closer to that of the home environment) scoring should be based on the setup that is closest to that of the home environment.

Trainers should assign scores based on the perceived need for assistance, even if assistance was not actually provided. There may be circumstances in which assistance may be needed but is not actually given. For example, a care director and caregiver may be communicating inappropriately early in the training process but the trainer has not yet developed the rapport necessary to intervene productively. In such situations, the trainer should assign a score based on the assistance he/she would have provided if circumstances permitted.

The TEAM Tool is designed to be completed at multiple points in time. The TEAM Tool is designed to be used at multiple time-points so that changes in skill level can be documented over time. The tool may be completed as often as deemed appropriate by the trainer(s). For purposes of pilot testing, the target windows for completion of the tool are:

- Within two weeks of admission to inpatient rehabilitation
- Near the midpoint of the inpatient rehabilitation stay (the middle two weeks of the stay, based on the best available information about anticipated discharge date)
- Within two weeks prior to discharge

If completion of the tool within these windows is not feasible, the research team will consult with trainers to identify appropriate timeframes.

9. Step-By-Step Instructions for Pilot-Testing of the TEAM Tool

1. **Select a day** within the target window to complete the TEAM Tool and obtain a TEAM Tool form. (Research staff will notify you of the window dates and will provide copies of the forms.)
2. **Fill out the date and ID fields** on the first page (research staff can fill in the remaining pages for you, unless you prefer to label them yourself).
 - ☐ Enter your clinician ID. IDs will be provided by the research staff.
 - ☐ Write the assessment date, which is the date on which you are completing the assessment form. All scores should be entered on the same day, based on observations made during care director and caregiver training during the week prior to (and including) the date on which you are completing the form. This period is referred to as the **look back period**.
 - ☐ Write the ID of the person with tetraplegia who is being trained. IDs will be provided by the research staff.
 - ☐ If a caregiver was trained during the look back period, enter the ID for that caregiver (also provided by research staff). Only one pairing of care director and caregiver should be assessed on a single TEAM Tool form. If more than one caregiver was trained during the look back period, enter the ID for the person who is most likely to be the primary caregiver and base your scores on the performance of this care director-caregiver team. (You may complete additional TEAM Tool forms for other caregivers if you wish, but this is optional.) If no caregiver was trained during this week, and you served the role of the caregiver during direction of care training, leave the caregiver ID blank.
3. **Complete scores for the tasks presented in Parts A and B.** For each task:
 - ☐ Determine if the task applies to the person with tetraplegia. Mark the task “NA” (not applicable) if:
 - It is not medically or functionally relevant to the person with tetraplegia (such as “Managing Wheelchair Parts” for someone who not a wheelchair user)
 - It does not require the assistance of a caregiver [such as “Mobility (Walking or Wheelchair) on Flat Surfaces” in the case of a person with tetraplegia who is being trained to be independent in power wheelchair mobility]
 - ☐ If the task is applicable, assign scale scores (Safety and Problem-Solving for Part A, Communication for Part B) as follows:
 - Use the scoring criteria on the bottom of page 2 of the TEAM Tool (and also described in this manual on page 13 to guide your scores.
 - Enter scores in the columns relevant to those who received training in the task during the look back period:
 - Blue column only: Only the care director (person with tetraplegia) received training
 - Blue and yellow columns: Care director and caregiver received training, but did not practice performing a task together

- **Blue, yellow, and green columns:** If both a care director and caregiver were trained and they practiced one or more tasks in that area together
 - A formal assessment is not necessary to enter a score of 1 (None) in any column—if the person (or team) being assessed has not received training or has not yet been asked to demonstrate any tasks within that area, enter a score of 1, indicating that they are not yet able to do any tasks in the task without assistance.
 - Leave a task blank only if it falls outside the scope of your practice (meaning that you do not provide any training relevant to this area and do not have expertise required to evaluate the performance.) If you wish, you may enter a dash in the box rather than leaving it blank.
 - Note that while inter-personal issues are often addressed by a psychologist, the tasks in the domain of Communicating Effectively are considered to be within the scope of all disciplines.
 - ❑ If there is another task in a domain that is relevant to the person with tetraplegia but is not addressed in other tasks (such as wound care), write this task on the line marked “_____ (Other)” and assign scores as discussed above.
4. **(Optional) Complete scores for the tasks presented in Part C.** The tasks in Part C are considered more advanced or otherwise may fall outside the scope of what is typically covered in inpatient rehabilitation, therefore this section is optional. It is included in recognition of the importance of these skills for long-term success in the community and to prepare for later piloting of the tool in settings beyond inpatient rehabilitation. If you choose to complete Part C, please follow the instructions listed in item 3 above for Parts A and B.
5. **Calculate Domain Scores.** *(If pressed for time, you may leave this to research staff to complete for you.)* Domain scores are calculated for each of the six domains: (Preventing Complications, Mobility in Daily Life, Personal Health and Appearance, Communicating Effectively, Home and Community Skills, Personnel Management Skills). Within each of these six domains, calculate domain scores for each column as follows:

Domain score = $X \div Y$

Where: X = Sum of the scores given to the tasks within the domain
(Enter this in the first blank of the “__ ÷ __” in the column)

Y = Number of tasks scored (not marked N/A or left blank) in the domain
(Enter this in the second blank in the “__ ÷ __” in the column)

If no scores appear in a particular column, leave the Domain Score lines blank.

6. **Calculate Overall Scores for Parts A, B, and C.** (You may leave this to research staff to complete for you.) Within each Part, calculate overall scores for each column as follows:

$$\text{Overall score} = P \div Q$$

Where: P = Sum of the scores given to the tasks within the Part
(Do not include the Domain Scores you calculated, only the scores for the tasks themselves. Enter in the first blank of the “__ ÷ __” in the Overall Score row.)

Q = Number of tasks scored in that Part
(Enter in the second blank in the “__ ÷ __”)

If no scores appear in a particular Part, leave the Overall Score lines blank.

7. **Note feedback on your experiences using the tool.** Space is provided on page 4 of the TEAM Tool packet for you to share comments about difficulties with scoring, tasks that were not included, uncertainties in the instructions, etc. The purpose of pilot-testing is to identify what works well and what does not, so all feedback is welcome.
8. **Return form to designated location for collection by the research team.** A member of the research team will collect the forms on a regular basis.

9. Resources on Care Direction and Caregiving
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<u>Title/Description</u>	<u>Accessible/Downloadable From</u>
A Step-by-Step Guide to Training and Managing Personal Assistants: Consumer Guide)	http://familyserviceswe.ca/sites/default/files/documents/a%20step-by-step%20guide%20to%20training.pdf
How to Successfully Hire and Manage a Personal Care Assistant: For People with Spinal Cord Injury (also available as iBook)	http://www.sfphysio.fr//docs/2015131740_how-to-successfully-hire-and-manage-a-personal-care-assistant-for-people-with-spinal-cord-injury.pdf
Managing Personal Assistants: A Consumer Guide (PVA)	http://www.pva.org/atf/cf/%7BCA2A0FFB-6859-4BC1-BC96-6B57F57F0391%7D/persasstfc6d.pdf
Personal Care Assistance: How Much Help Should I Hire	https://craighospital.org/resources/personal-care-assistance-how-much-help-should-i-hire
Personal Care Assistants: How to Find, Hire, & Keep	https://craighospital.org/resources/personal-care-assistants-how-to-find-hire-keep
Long Term Caregivers: For Better and For Worse	https://craighospital.org/resources/long-term-caregivers-for-better-and-for-worse
As the Years Go By: Accepting New Help	https://craighospital.org/resources/as-the-years-go-by-accepting-new-help
Video: Perspectives From Those Providing Care	http://sci.washington.edu/care_providers/index.asp
Video: Managing Personal Caregivers: A Panel Discussion	http://sci.washington.edu/caregivers/index.asp
Video: Personal Caregivers: Tips, Tricks and Tales from Individuals with Spinal Cord Injury	http://sci.washington.edu/info/forums/reports/caregivers.asp
SCI Forum Report – Personal Care Attendants	http://sci.washington.edu/info/forums/reports/attendant.s.asp
The Rough Guide to Managing Personal Assistants	http://www.independentliving.org/docs6/vasey2000.html
Caring for Caregivers – SCI InfoSheet	http://www.spinalcord.org/resource-center/askus/index.php?pg=kb.page&id=299
Long Term Caregivers: For Better and For Worse	https://craighospital.org/resources/long-term-caregivers-for-better-and-for-worse
Hiring In-Home Help – Family Caregiver Alliance	https://www.caregiver.org/hiring-home-help

Building Positive Working Relationships Between People with SCI and Caregivers

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Objective: To present suggestions for fostering positive interpersonal dynamics between people with spinal cord injury (SCI) and their caregivers identified in discussions with people with tetraplegia, caregivers, and SCI clinicians.

Design: Qualitative analysis of data acquired through focus groups.

Participants/Methods: Focus groups were conducted with people with tetraplegia due to SCI who have experience directing their care (n= 26), family and/or hired caregivers (n=13), and SCI clinicians (n=25) as part of a larger project whose objective was to create an assessment tool for direction of care/caregiving skills. Discussion topics included learning to direct and provide care, characteristics of good direction of care and caregiving, suggested topics for training and other related experiences. Recordings of the discussions were transcribed and imported into NVivo for coding by primary and secondary themes. Interpersonal dynamics emerged as a key theme. Subthemes that discuss suggestions for promoting positive working relationships between caregivers and people with SCI are presented here.

Results: Key suggestions included: (1) Set and document expectations early in a collaborative process that involves both the person with SCI and caregiver. (2) Explain not only WHAT needs to be done, but WHY to avoid the perception of being “picky” and to give respect to the contributions caregivers make to health and function. (3) Respect each other’s expertise. (4) Acknowledge when things don’t feel right so that a solution can be identified early. (5) Be flexible and open to collaboratively finding new ways of doing things. (6) Periodically step back and re-assess the big picture of how the dynamics feel to identify areas for improvement or strengths to cultivate. (7) Treat one another as you would like to be treated.

Conclusion: Interpersonal dynamics play a key role in the success or failure of the care experience. Through trial, error, and experience, people with SCI and their caregivers have identified strategies for promoting mutual respect and successful collaboration. Findings from this investigation will inform the development of consumer education materials to promote positive relationships.

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Presented by:
Jeanne M. Zanca, PhD, MPT
Kessler Foundation
West Orange, New Jersey

SEPTEMBER 4-7, 2016 • OMNI NASHVILLE & MUSIC CITY CENTER HOTEL

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Objective

- To present suggestions for fostering positive interpersonal dynamics between people with spinal cord injury (SCI) and their caregivers.



Background

- People with tetraplegia due to SCI with significant loss of movement require assistance from others for most activities
- Average hours of care/day reported to range from 7 to 19, depending on the level of injury (Robinson-Whelen and Rintala 2003; Prince et al, 1995)
- Care may be provided by “informal” caregivers (spouse, other family, friends, etc.), paid caregivers, or a combination of both (Walker et al, 2015; Boschen et al 2005; Lucke et al 2004; Robinson-Whelen and Rintala 2003; Weitzenkamp et al 2002; Unalan et al 2001)
- Appropriate personal assistance is critical to maintain health and hygiene, prevent secondary complications, avoid institutionalization, and participate in family and community roles



Background

- Data collected in the context of a larger study whose aim is to create an assessment tool for direction of care and caregiving skills
- Participants frequently discussed importance of positive interpersonal dynamics with caregivers
- Analyses presented here focus on themes related to fostering healthy relationships



Methodology

- Focus groups were conducted with:
 - People with tetraplegia due to SCI (n = 26):
 - Injured for at least 1 year
 - Experience directing their care
 - Family and/or hired caregivers with at least six months experience providing care to a person with tetraplegia due to SCI (n = 16)
 - SCI clinicians involved in training people with tetraplegia and caregivers in inpatient rehabilitation (n = 25)



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Methodology

- Focus groups took place at Kessler, Shepherd Center, and VANJHCS
- Discussion questions developed with input from all investigators
- Two hour discussions were facilitated by lead investigator (JZ)
- Discussion topics included:
 - Process of learning to direct and provide care
 - Characteristics of good direction of care and caregiving
 - Suggested topics for training
 - Other experiences related to direction of care and caregiving
- Discussions were recorded for later transcription



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Methodology

- Transcripts compared with audio recordings and corrected as needed (notes and audio recordings were reviewed for VA-based groups due to delays in transcription process)
- Transcripts were reviewed by three investigators
- Initial list of primary themes and subthemes identified by lead investigator, then reviewed by co-investigator who suggested additions and revisions
- Final list of themes determined by consensus
- Themes related to promoting positive working relationships between caregivers and people with SCI are presented here in the form of suggestions for others



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Participant Characteristics

People with Tetraplegia

	Kessler	Shepherd	VANJHCS
n	9	8	9
Age in Years [Median (Range)]	44 (29–67)	45 (30-61)	59 (43-81)
Sex [% Male]	67	57	100
Ethnicity [%Hispanic]	11	0	11
Race [% Caucasian]	56	57	33
Years Post-Injury [Median (Range)]	16 (2-50)	20 (1-44)	21 (2-38)
Paid Hours of Care Received Per Week [Median (Range)]	37 (6-56)	35 (9-72)	36 (0-140)
Unpaid Hours of Care Received Per Week [Median (Range)]	10 (2-12)	12 (0-24)	24 (2-168)



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Participant Characteristics

People with Tetraplegia

	Kessler	Shepherd	VANJHCS
n	9	8	9
Age in Years [Median (Range)]	44 (29–67)	45 (30-61)	59 (43-81)
Sex [% Male]	67	57	100
Ethnicity [%Hispanic]	11	0	11
Race [% Caucasian]	56	57	33
Years Post-Injury [Median (Range)]	16 (2-50)	20 (1-44)	21 (2-38)
Paid Hours of Care Received Per Week [Median (Range)]	37 (6-56)	35 (9-72)	36 (0-140)
Unpaid Hours of Care Received Per Week [Median (Range)]	10 (2-12)	12 (0-24)	24 (2-168)



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Participant Characteristics

Caregivers

	Kessler	Shepherd	VANJHCS
n	4	7	5
Age in Years [Median (Range)]	61 (24– 70)	52 (43-61)	63 (24-74)
Sex [% Male]	25	14	20
Ethnicity [%Hispanic]	25	0	0
Race [% Caucasian]	50	14	60
Years of Experience Providing Care [Median (Range)]	15 (3-25)	15 (1-35)	4 (2-38)
Hours of Care/Week Provided [Median (Range)]	30 (8-100)	48 (4-120)	40 (10-168)
% Hired (vs. Informal)	25	71	0



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Participant Characteristics

Caregivers

	Kessler	Shepherd	VANJHCS
n	4	7	5
Age in Years [Median (Range)]	61 (24– 70)	52 (43-61)	63 (24-74)
Sex [% Male]	25	14	20
Ethnicity [%Hispanic]	25	0	0
Race [% Caucasian]	50	14	60
Years of Experience Providing Care [Median (Range)]	15 (3-25)	15 (1-35)	4 (2-38)
Hours of Care/Week Provided [Median (Range)]	30 (8-100)	48 (4-120)	40 (10-168)
% Hired (vs. Informal)	25	71	0



Participant Characteristics

SCI Clinicians

	Kessler	Shepherd	VANJHCS
n	9	9	7
Age in Years [Median (Range)]	39 (28-59)	41 (25-46)	41 (35-53)
Sex [% Male]	0	22	17
Ethnicity [%Hispanic]	0	0	0
Race [% Caucasian]	89	89	17
Discipline [%]			
Nursing	22	33	33
Occupational Therapy	33	33	17
Physical Therapy	33	33	17
Other	11	0	33
Years SCI Rehab Experience [Median (Range)]	12 (4-37)	8 (3-13)	10 (7-21)



Participant Characteristics

SCI Clinicians

	Kessler	Shepherd	VANJHCS
n	9	9	7
Age in Years [Median (Range)]	39 (28-59)	41 (25-46)	41 (35-53)
Sex [% Male]	0	22	17
Ethnicity [%Hispanic]	0	0	0
Race [% Caucasian]	89	89	17
Discipline [%]			
Nursing	22	33	33
Occupational Therapy	33	33	17
Physical Therapy	33	33	17
Other	11	0	33
Years SCI Rehab Experience [Median (Range)]	12 (4-37)	8 (3-13)	10 (7-21)



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Suggestions for Fostering Positive Interpersonal Relationships



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Suggestions

1. Set expectations early.
2. Explain not only WHAT needs to be done, but WHY.
3. Respect each other's expertise.
4. Be flexible and open to new ways of doing things.
5. Acknowledge when things don't feel right.
6. Step back and re-assess the big picture.
7. Treat one another as you would like to be treated.
8. Pick your battles.



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1. Set expectations early.

- Being “on the same page” is very important for a team to function well.
- Important to discuss:
 - What care tasks are needed and when
 - Schedule (including arrangements for each caregiver to have breaks during the day and days off)
 - Amount of notice needed for changes in schedule
 - “Ground Rules” about cell phone use, handling personal mail, reserving personal space for both parties, participation in social situations, etc.
 - Who has authority to direct care (person with SCI vs. spouse or others in household)



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1. Set expectations early.

- Ideally, both the person who requires assistance and the caregiver(s) should be involved in establishing expectations.
- Checklists, contracts, or other mechanisms for documenting expectations may be helpful.
 - Reminds everyone of what was discussed
 - Can make discussions less awkward later if something isn't being done as planned
 - Can help coordinate communications among caregivers when there are multiple people providing care over the day or week



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1. Set expectations early.

"It's also key that you put it all out in front--you're clear about what is expected. It's a benefit for both the person who's going to be the caregiver and yourself, to lay out exactly 'this is what I'm going to need,' 'this is what you have to do,' and be as detailed as possible, so that there are no surprises when you're actually doing this."

– Person with Tetraplegia



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1. Set expectations early.

“I am someone who is intensely private...I want my caregiver to have a very clear understanding. I want you to open [my mail], I might need you to pull it out and unfold it, but at that point, put it down, step away.”

– Person with Tetraplegia



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2. Explain not only WHAT needs to be done, but WHY.

- The needs and preferences of each person with tetraplegia are unique
- Doing things in a very specific way is important
 - For health or functioning (preventing infections, for example)
 - To respect the autonomy of the person with SCI
- Explaining WHY something needs to be done a certain way can:
 - Prevent perceptions of the recipient of care being “picky” or “bossy” by giving credibility to the request
 - Give value to caregivers’ efforts and convey respect for their contributions (and, in turn, enhance morale and motivation)
 - Increase the likelihood that things will be done the desired way



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2. Explain not only WHAT needs to be done, but WHY.

"I explain to them I want the coffee here, not because I'm ...a dictator, but why it needs to be here. Because I can reach it, I'm more independent...So explaining to them why you need certain things, when you need them, where you need them, and how you need them. Then they feel more like they're helping you, not that they're your servant."

– Person with Tetraplegia



3. Respect each other's expertise.

- Each member of the care team (person with tetraplegia and caregiver) brings something to the table.
 - People who live with SCI have requirements and preferences for how things should be done and often know the signs and symptoms that indicate something is wrong (spasticity, dysreflexia, etc.).
 - Caregivers may be in a position to observe things that the person with tetraplegia cannot see or feel.
- Share what you observe, and consider each other's perspectives when determining how to proceed.



3. Respect each other's expertise.

"I know different kind of spasms, what's causing them. So knowing your body—I know I have different types of spasms. One might be from ...not taking my medication. Others might be from some kind of a pain."

– Person with Tetraplegia

"After the appendix ruptured, they let him out of the hospital after several weeks. He received an impaction and we knew right away because we can tell how much is normal for his bowel movements and things like that."

– Caregiver



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4. Be flexible and open to new ways of doing things.

- There are many ways to accomplish tasks of daily living that are not necessarily known by medical professionals – bathing, turning, lotioning, massage, etc.
- Each person has different capabilities, which may influence how things are best done.
- Sometimes it takes trial and error by the person receiving care *and* the caregiver to find creative solutions to tasks and challenges.
- Listen to each other and consider each other's suggestions.



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4. Be flexible and open to new ways of doing things.

“A lot of times when you're a caregiver, it's a lot of trial and error and as long as the consumer you're working with isn't afraid to try things, well then—he's got a good thing going there.”

- Caregiver



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5. Acknowledge when things don't feel right.

- Explaining how to do something is not easy.
- Different people learn different ways.
- Everyone has misunderstandings sometimes.
- Watch for signs of uncertainty or frustration, which could mean something is not being communicated well.
- If something feels wrong, acknowledge it.
- Getting these issues out in the open early on can avoid creating bigger problems down the road.



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5. Acknowledge when things don't feel right.

"...You can say the same thing over, three different ways, but if that's not how they learn, you're not going to accomplish anything...If I direct something in a specific way and it's clear they're not grasping it, then I say 'How can I do this better? Like 'How can I help you help me?'"

- Person with Tetraplegia



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6. Step back and re-assess the big picture.

- It can be easy to get caught up in the details of day-to-day care.
- Ask each other:
 - How did the day go for you?
 - What worked well? What could have been better?
 - Was the day frustrating or satisfying?
- Taking time to think about how things are going in general can help identify challenges and solutions that might not otherwise be found.



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6. Step back and re-assess the big picture.

"I think first is respect the patient [person with SCI]. You know, being there. Listening to the patient [person with SCI]. And asking for feedback from them... 'So how was the day? What did you think needed to be different?'"

- Caregiver



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7. Treat one other as you would like to be treated.

- Say "please" and "thank you."
- Use a kind tone of voice and respectful language.
- Be patient. Acknowledge that everyone has good days and bad days.
- Treating each other well builds and maintains a foundation of trust that is essential for navigating times when things don't go so well.



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7. Treat one other as you would like to be treated.

"I think you have to treat the person that you're dealing with nicely. That's what it comes down to. Because if you treat somebody like a jerk it's going to come boomeranging right back at you. Either they're going to [give] poor care or are going to leave on you."

- Person with Tetraplegia

"I have an aide right now, we been together for a while, there's little idiosyncrasies that come up once in a while that drive me crazy, and I'm sure I do the same thing to her. But you have to be flexible, I think, no matter who it is."

- Person with Tetraplegia



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8. Pick your battles.

- Even with instructions, caregivers don't always do what you would like them to do.
- Too much criticism may damage the relationship or cause your caregiver to leave.
- Decide what you can live with and what you can't.
- Focus your feedback on what is most important.



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8. Pick your battles.

"I try my best not to complain as much, because then when you do complain then they take it a little more serious...So don't complain so much, but when it's serious, complain, when need be. Try to bite your tongue a little bit, but at the end of the day I try to do what I can to make myself happy and go on with my life."

- Person with Tetraplegia



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Discussion

- Limitations
 - Focus group question guide not developed with relationship-building as a primary focus
 - Greater depth of feedback might have been forthcoming with different questions
 - People with tetraplegia often discussed interactions with paid caregivers
 - Other suggestions may have emerged if focus was placed on informal caregiver relationships



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Discussion

- Limitations (continued)
 - Civilians (and/or caregivers of civilians) have greater representation in the overall sample
 - Delays in transcription made in-depth analysis more difficult for veteran-affiliated groups
 - Differences between veteran and civilian-derived feedback were not specifically examined in this analysis (but will be assessed in the future)



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Discussion

- Key Ideas
 - Strong interpersonal skills are key to successful direction of care and caregiving
 - Working successfully with caregivers requires mutual respect and a delicate balance of assertiveness and flexibility
 - Much is learned through trial and error



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Discussion

- Application to Practice
 - Important to devote time and effort to developing interpersonal skills
 - Suggestions presented here could inform development of education materials and programs for people with tetraplegia and caregivers
 - Peer-mentoring by experienced people with tetraplegia and/or caregivers likely plays an important role in interpersonal skill development and problem-solving



Thank You

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Building Positive Working Relationships Between People with SCI and Caregivers

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Learning to Direct Care After Spinal Cord Injury

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Objective:	To better understand challenges faced and lessons learned by people with tetraplegia due to SCI as they become skilled in directing their own care in the community.
Design:	Qualitative analysis of data acquired prospectively through focus groups.
Setting:	Gathering of community-dwelling people with SCI.
Participants:	Twenty-six people with chronic (≥ 1 year) tetraplegia resulting from traumatic or non-traumatic SCI who provide direction to caregivers on a daily basis as they assist with self-care and other activities.
Interventions:	Not applicable.
Main Outcome Measures:	Themes identified through content analysis.
Results:	Challenges encountered when learning to direct one's care included: (1) difficulty engaging in direction-of-care training during inpatient rehabilitation because of denial or difficulty accepting long-term care needs; (2) overwhelming volume of information presented in a short time during inpatient rehabilitation; (3) differences in physical and other characteristics between the hospital setting and "the real world"; (4) not yet understanding their post-SCI body; (5) hesitance to criticize caregivers because of feelings of vulnerability, wanting to avoid nitpicking, and/or fear of retaliation; (6) lack of assistants who are knowledgeable about SCI. Participants stressed time, experience, paying attention to one's body (particularly for signs of complications), speaking with peers with SCI, communicating clearly, and learning when to let go and when to speak up as factors that helped them direct care more effectively.
Conclusions:	The ability to direct one's care is a complex skill that is developed over time, and requires self-awareness, self-confidence, and strong communication skills. Efforts to prepare people with new SCI to direct care effectively should provide opportunities for real-world practice, cultivate awareness of one's body, address strategies for communicating effectively with caregivers, and provide opportunities to discuss direction of care with experienced peers.

Learning to Direct Care After Spinal Cord Injury

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INTRODUCTION AND OBJECTIVE

- Assistance from others is critical to enable people with substantial motor deficits due to tetraplegia to live successful and healthy lives in the community.
- The ability to instruct others in how to provide assistance (known as "direction of care") is important to ensure that needs are met and prevent complications. The process of learning to direct one's care typically begins in inpatient rehabilitation.
- Direction of care skills empower people with substantial physical limitations to have control over their care and environment and facilitate participation in activities of importance to them.

The objective of this analysis is to better understand challenges faced and lessons learned by people with tetraplegia due to spinal cord injury (SCI) as they become skilled in directing their own care.

METHODS

Context. These data were collected as part of a larger study whose aim is to create a tool to assess the ability of people with tetraplegia to direct their care and the ability of caregivers to provide appropriate assistance.

Participants. People with tetraplegia due to SCI who:

- (1) Had SCI for at least 1 year
- (2) Had at least six months experience directing caregivers on a regular basis

Data Collection Procedures:

- Focus groups took place at Kessler, Shepherd Center, and VANJHCS
- Discussion questions developed with input from all investigators
- Two hour discussions were facilitated by lead investigator (JZ)
- Discussion topics included:
 - Process of learning to direct care
 - Characteristics of good direction of care
 - Suggested topics for training people with tetraplegia how to direct care
 - Other experiences related to direction of care and working with caregivers
- Discussions were recorded and transcribed

Data Analysis:

- Transcripts were reviewed by three investigators
- Initial list of primary themes and subthemes identified by lead investigator, then reviewed by co-investigator who suggested additions and revisions
- Final list of themes determined by consensus
- Current analysis focuses on themes related to barriers and facilitators to learning to direct one's care

RESULTS

Challenges encountered when learning to direct care included:

1. Difficulty engaging in inpatient direction-of-care training due to denial of one's long-term needs.

"...The first two or three months that I was here I wasn't trying to hear about, 'You're going to have to get a suppository or you have to get called,' or anything like that. I was like 'I'm going to get better, my spinal cord is going to heal in a couple months, I'm going to go hard in therapy and I'm going to be fine. I'm going to be running around, I'm not going to have to worry about this.'"

"They throw so much at you. It's a lot to remember. You can't even begin to imagine what life is going to be like when you get home."

3. Differences between the hospital setting and "the real world."

"When I came home I was like, 'oh how am I supposed to do this?' Because the way I was doing it was on the bed, and then transferring. But then when I got home it just doesn't quite work that way."

4. Not yet understanding one's post-SCI body.

"When you come out of here you're so raw, you have no idea. I think I only stayed here for two months, and it was such a shock, I was 24 years old, independent, just starting my life, and I had no idea...Then when you go home, how are you going to teach somebody if you don't know yourself?"

5. Hesitance to criticize caregivers because of feelings of vulnerability, wanting to avoid nitpicking, and/or fear of retaliation.

"How do you lie in bed in need of certain services, certain care, direct your employee? Now, how do you reprimand them and give them direction without worrying about retaliation, passive aggressive stuff? It's so tough."

6. Lack of assistants who are knowledgeable about SCI.

"A lot of the aides had no idea. They just thought that you had a broken bone or something like that. So, they didn't understand some of the neurological things that if you had an accident or you spasms or something like that—they thought that it was something that they were doing or they would kind of be hesitant trying to move you."

Factors that facilitated more effective direction of care included:

1. The experience that comes with time.

"I think the only way to do it is time and experience. Unfortunately, your bowels have to touch your urological equipment and you gotta get E. coli and you've got to get your urinary tract infection, you've got to get your first emergency room visit and stuff like that, and until that really happens you don't know."

2. Paying attention to your one's body and changes in it (particularly signs of complications).

"I know different kind of spasms, what's causing them. So knowing your body—I know I have different types of spasms. One might be from ...not taking my medication. Others might be from some kind of a pain."

3. Speaking with peers with SCI about their experiences.

"You see other guys, you talk about your problems, and you learn 'he's doing that, I'll try that'...We'd all talk about similar issues, similar things that are going on with us...When I see other people, you can share information and you gain knowledge that way too."

4. Learning to communicate clearly and specifically what needs to be done and why.

"I explain to them I want the coffee here, not because I'm ...a dictator, but why it needs to be here. Because I can reach it, I'm more independent...So explaining to them why you need certain things, when you need them, where you need them, and how you need them."

5. Learning when to let go and when to speak up.

"I try my best not to complain as much, because then when you do complain then they take it a little more serious...So don't complain so much, but when it's serious, complain, when need to. Try to bite your tongue a little bit, but at the end of the day I try to do what I can to make myself happy and go on with my life."

Table. Characteristics of Focus Group Participants with Tetraplegia			
	Kessler	Shepherd	VANJHCS
n	9	8	9
Age in Years [Median (Range)]	44 (29-67)	45 (30-61)	59 (43-81)
Sex (% Male)	67	57	100
Ethnicity (%Hispanic)	11	0	11
Race (% Caucasian)	56	57	33
Years Post-Injury [Median (Range)]	16 (2-50)	20 (1-44)	21 (2-36)
Paid Hours of Care Received Per Week [Median (Range)]	37 (6-56)	35 (9-72)	36 (0-140)
Unpaid Hours of Care Received Per Week [Median (Range)]	10 (2-12)	12 (0-24)	24 (2-168)

DISCUSSION

Limitations

- Civilians (and/or caregivers of civilians) have greater representation in the overall sample; reported fewer hours of unpaid care than veterans
- Delays in receipt of transcripts made in-depth analysis more difficult for veteran-affiliated groups
- Greater discussion of interactions with paid caregivers than with family caregivers (other barriers/facilitators may be pertinent to those interactions)

Conclusions

- The ability to direct one's care is a complex skill that is developed over time, and requires self-awareness, assertiveness, and strong communication skills.
- Efforts to prepare people with new SCI to direct care effectively should
 - (1) provide opportunities for real-world practice
 - (2) cultivate awareness of one's body,
 - (3) address strategies for communicating effectively with caregivers,
 - (4) encourage discussion of direction of care with experienced peers.

CDMRP
COMMUNITY DEVELOPMENT RESEARCH PROGRAM

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